

Defining Essential Services for Families Affected by FAS/FAE

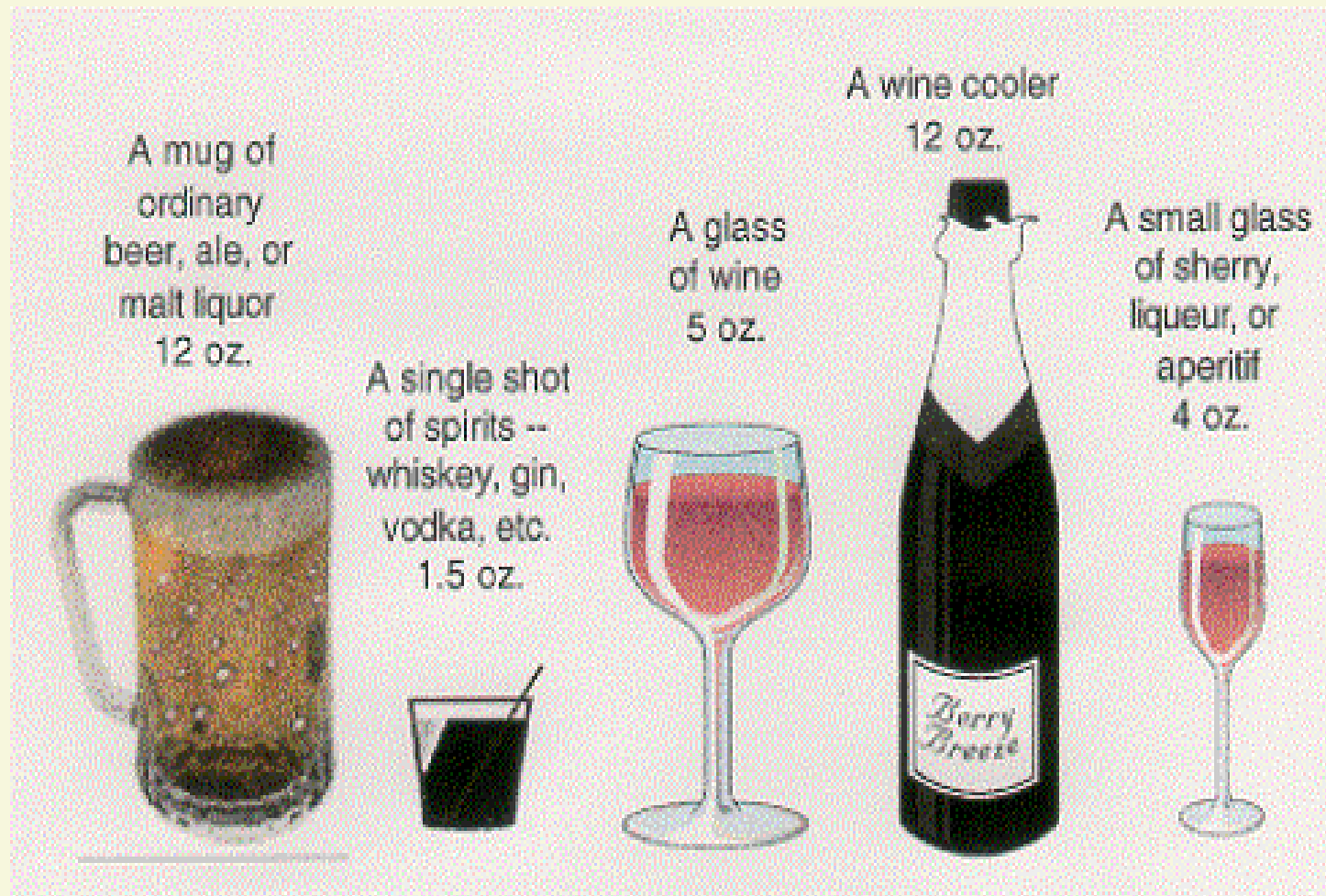
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Presentation Overview

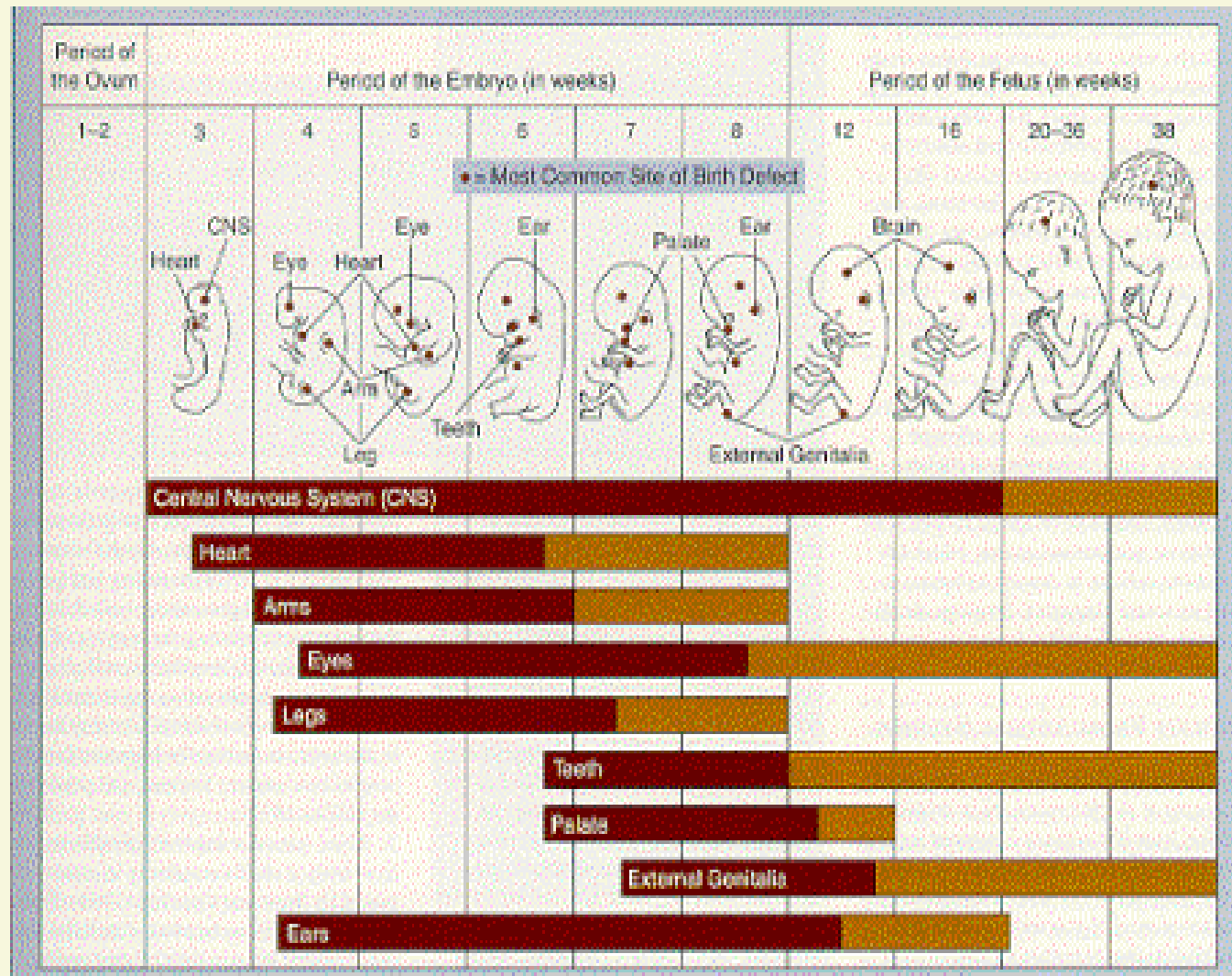
- Overview of FAS
 - Effect of FAS on the Fetus
 - Diagnostic Criteria for Fetal Alcohol Syndrome and Related Disorders
 - Developmental Implications
 - Intervention Strategies (in a nutshell!)
- Effect of FAS on Family Functioning
- Essential Services for Families: Can we find them in Wisconsin?

Alcohol and Drug Use During Pregnancy

Standard Drink



Development of the Embryo

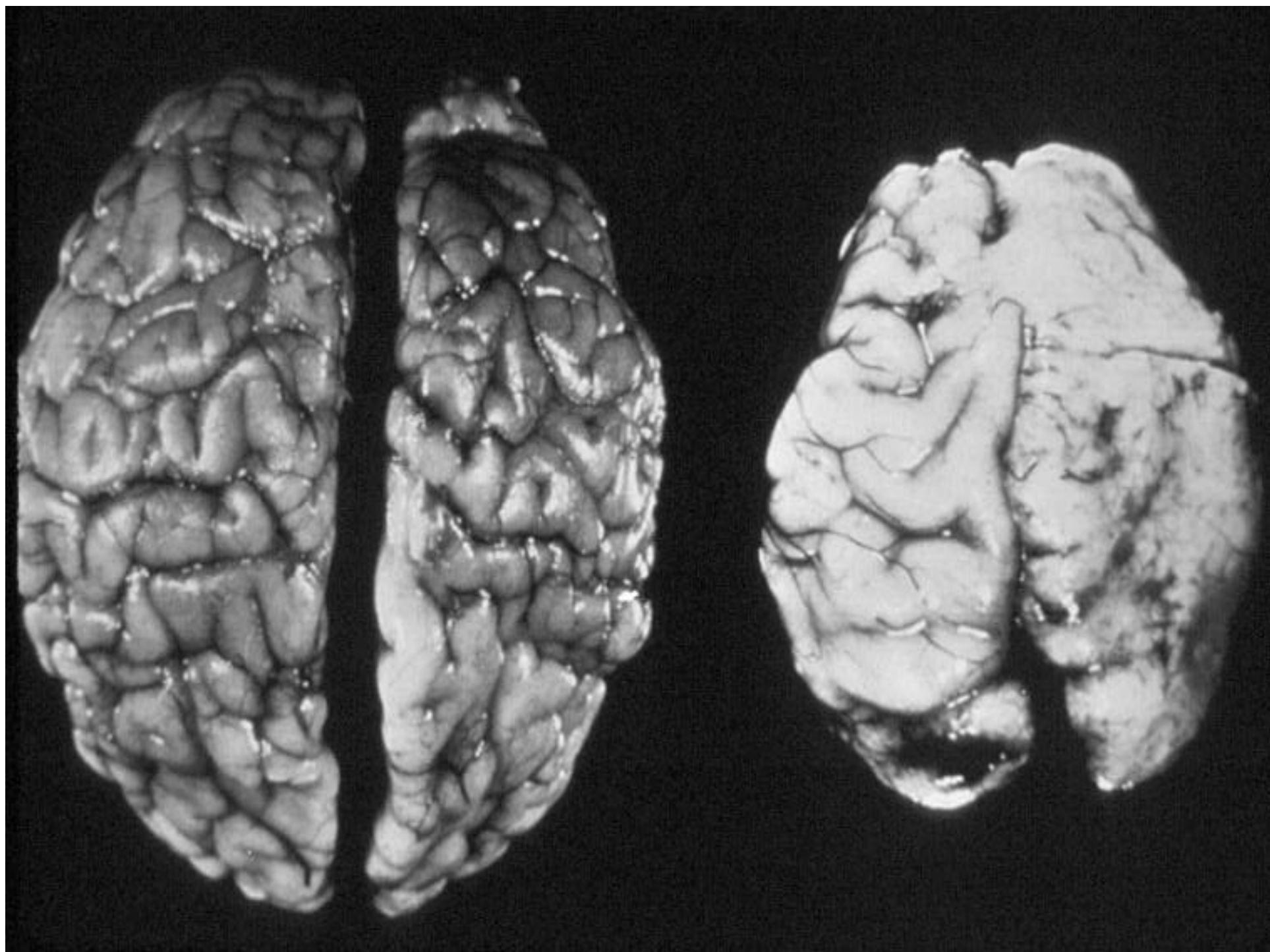


Coles, 1994

Brain Regions Affected

- Fetal brain particularly sensitive to alcohol during 3rd trimester
 - Cerebral cortex exhibits abnormal patterns in distribution of neurons and abnormal neurotransmission
 - Hippocampus and cerebellum have decreased cell numbers and altered neurochemical activity
 - Corpus callosum appears absent or poorly developed in many (evidenced by MRI)
 - Size and volume of cerebellum and basal ganglia are reduced

- Fleming et al., 1999



Etiology

- Etiology at a molecular level is not fully known
- Severity of effects depends on dose, pattern, and timing of alcohol exposure

What is Fetal Alcohol Syndrome (FAS)?

Fetal Alcohol Syndrome:

A specific, although variable, constellation of abnormalities seen in certain offspring who have been exposed to high levels of alcohol during gestation.

Major signs leading to a diagnosis of FAS

- Central Nervous System effects
- Small size and weight
- Specific facial features
- History of prenatal alcohol exposure

Central Nervous System Effects

- Mental retardation or learning disabilities may be present
- I.Q. Range 30-130
- Other possible effects:
 - *Hyperactivity
 - *Distractibility
 - *Motor Problems
 - *Memory Problems
 - *ADD/ADHD
 - *Attachment concerns
 - *Inability to appreciate consequences of behavior

Small Size and Weight

- Length and weight both before and after birth are smaller than normal
- Head is smaller than normal (microcephaly)
- Body tends to be thin

Specific Facial Features

- Short palpebral fissures
- Flat, elongated philtrum
- Thin upper lip
- Lower set ears
- Small chin
- Flattened cheeks/face

Facies in Fetal Alcohol Syndrome

Discriminating Features

short palpebral fissures

flat midface

short nose

indistinct philtrum

thin upper lip

Associated Features

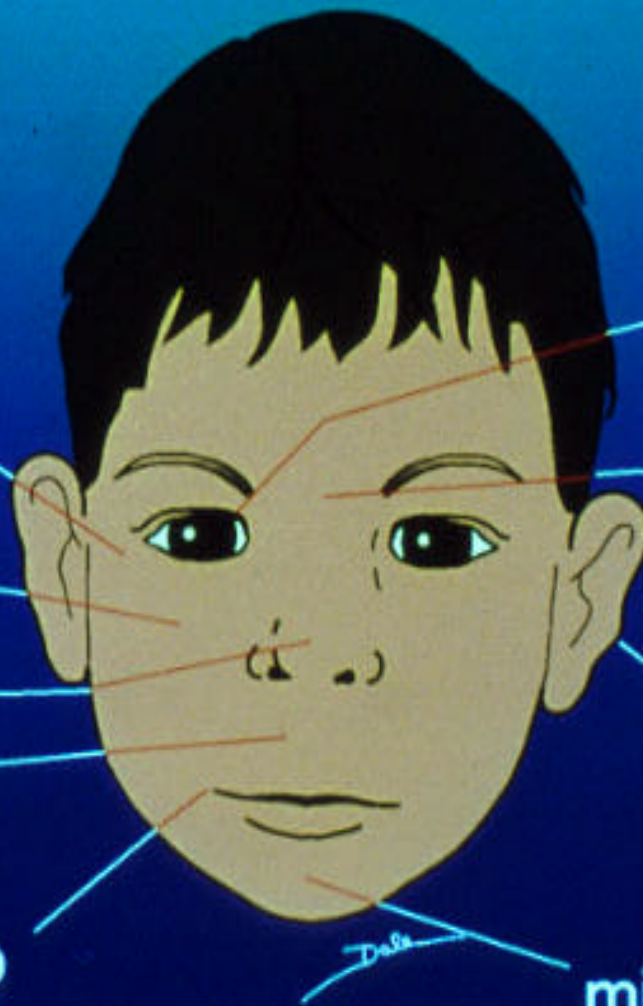
epicanthal folds

low nasal bridge

minor ear anomalies

micrognathia

In the Young Child



Individuals with FAS

- The following slides are credited to Ann Streissguth and Ruth Little in a slide training package, "Alcohol, Pregnancy, and the Fetal Alcohol Syndrome."
 - Copyright 1994











FAE

If a child has some, but not all of these signs coupled with a history of prenatal alcohol exposure, the child may be identified as having **Fetal Alcohol Effects (FAE)**.

NIAAA, NIH

- Growth Retardation
- Facial Malformations
- Neurodevelopmental Disorder
- Other Physical Abnormalities

FAS=Exposure + 1 + 2 + 3

FAS without exposure=1+2+3

Partial FAS=Exposure+some 2+ 1, 3,
and/or 4

ARND=Exposure + 3

ARBD=Exposure + 4

*Warren & Foudin, 2001
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So What???

Developmental Implications

Primary Disabilities Include:

- Poor habituation
- Failure to thrive
- Delays in physical and cognitive development
- Distractibility/hyperactivity
- Memory deficits
- Impulsivity
- Difficulty in abstracting abilities/executive functioning
 - Difficulty predicting or understanding consequences of behavior
 - Concrete learner and literal translator

Other concerns:

- Academic ceiling often reached: usually 4th grade for reading, 3rd grade for spelling and arithmetic
- Impulsive, aggressive, unpredictable, and sometimes violent behavior
- Mental Health Issues
 - Depression
 - Substance abuse
 - Bi-polar disorder

Secondary Concerns

- Irritability, temper tantrums
- Disobedience
- Difficulty following directions
- Inability to adapt to changes in the environment
- Decreased numbers of friends
- Perceived and real “lying,” stealing, disobedience

Developmental gaps in FAS/ARND

- Age 5 going on 2 developmentally
- Age 6 going on 3 developmentally
- Age 10 going on 6 developmentally
- Age 13 going on 8 developmentally
- Age 18 going on 10 developmentally

• Malbin, 2001

Secondary Disabilities of FAS/FAE

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Secondary Disabilities

- Mental Health Problems
- Disrupted School Experience
- Trouble with the Law
- Confinement
- Inappropriate Sexual Behavior
- Alcohol/Drug Problems

Now What???

Change the Individual ??

Modify the
Environment ??

Strategies for Working with Individuals with FAS/FAE

- Structure
- Predictability
- Monitored level of stimulation
- Recognized retention difficulties
- Multi-modality instruction
- Repetition

Effect of FAS on Family Functioning

The Effect of FAS on Family Functioning (Wilton, 2002)

- Interview study of mothers (N=85) raising a child with:
 - FAS
 - FAE/ARND
 - Suspected FAS/ARND
- Variables:
 - Income, Social Support, # of Parents in the Home, Family Hardiness, Coping, Diagnostic Category of Child
 - Family Distress, Parental Negative Emotion (Anger + Depression)

Findings

- There is a difference in family distress and parental negative emotion based on the child's diagnostic category
 - FAS
 - FAE/ARND
 - Possible FAS/ARND

Findings (cont.)

- Families raising a child with FAS experienced significantly lower distress than those raising a child with FAE or possible FAE
- Families raising a child with either FAS or FAE experienced significantly less negative emotion than families raising a child with possible FAS/E

Findings (cont.)

- There is a sig. relationship between family hardiness and both family distress and parental negative emotion
 - As hardiness **increased** both family distress and parental negative emotion **decreased**
 - Supports findings of other research on families and developmental disabilities
 - McCubbin et al., 1988; Failla & Jones, 1991
- **NO** sig. relationship between between social support, number of parents in the home or coping and family distress or parental negative emotion

Family Hardiness

- A particular strength possessed by a family, a “durability” that can buffer stress in families. Components include:
 - Confidence
 - Control
 - Commitment
 - McCubbin et al., 1996
- Measured by *Family Hardiness Index*

Family Hardiness Index

- In our family...
 - Trouble results from the mistakes we make
 - It is not wise to plan ahead and hope because things do not turn out anyway
 - Our work and efforts are not appreciated no matter how hard we try and work
 - Life seems dull and meaningless
 - We seem to encourage each other to try new things and experiences
 - Family Hardiness Index
 - © 1996 University of Wisconsin-Madison

FHI Applicability with FAS ??

- In our family...
 - It is better to stay at home than go out and do things with others
 - When our family plans activities we try new and exciting things
 - We tend to do the same things over and over...it's boring

Implications Essential Services for Families Affected by FASD

Essential Services

- Appropriate counseling
 - Individual
 - Family
- Assessment/Diagnostic Services
- Informed Professionals
 - Medical (incl. mental health), education
- Support
 - Family, community
- Accurate, up-to-date information, non-threatening

Counseling

- We can target family functioning in areas that are known to be associated with resiliency and coping:
 - Internal locus of control
 - Family cohesiveness
 - Positive outlook
 - Encouraging exploration (even with the constraints of FAS and related issues)
 - Positive Behavior Support

Facilitate a comprehensive screening/diagnosis

- Include adaptive behavior in addition to IQ
- Demand accurate reporting (e.g., band scores for IQ tests; comprehensive written reports with treatment plans/suggestions)
- Seek out a trained clinician (e.g., geneticist/dysmorphologist) to diagnose FAS
- Don't rely on physicians to be the experts: come prepared

Informed Professionals

- Targeted professional education
 - In-service
 - On-line education
 - Health and Social Service Providers
 - Educators
 - Criminal Justice Professionals
 - Lawyers, judges, police/parole officers, guards

Family Empowerment Network (FEN)

- Support, resource and referral network on FAS for families and professionals

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Questions ??